

What Happens to Data After a Research Study?

Data that identifies you is saved with your consent

After a clinical trial, most regulatory agencies require researchers to keep data for at least a few years. This will be outlined in the consent form.

Even after a clinical trial, data could be helpful to:



Answer additional research questions



Inspire future clinical research



How is data kept?

Clinical trial data is usually kept as either anonymized or coded data. Only rarely is data saved in an identifiable way.

Anonymized Data



Personal details are removed from the health data.

Examples of personal data:

- Name
- Date of birth
- Address
- Medical Record Number

In other words, health information cannot be linked back to you.

Coded Data



A code is created to link health information to an identity. The code is like a key that can unlock the identity linked to the data.

Once coded, only a few approved people have access to that code. Access to the code is restricted, so privacy is protected.

Identifiable Data



Data is identifiable when that health information can be linked back to you.

Coded data is only identifiable to people with access to the code.

Identifiable data is only shared with approved researchers if you give consent.

You have the right to ask questions about your data.

- Can I see my data?
- What data will be saved?
- Can the saved data be linked back to me?
- How long will you keep my data?
- Can I choose how my saved data is used?
- How will my data be shared? With whom?
- Will my data be sold? Will I be paid for my data?

